Aebruska State Legislature

#### SENATOR COLBY COASH

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October 15, 2014

### Introduction

As stated in LR574, there is a substantial percentage of individuals in the United States who are deaf and hard of hearing. Across the nation, there has been a growing interest in fully integrated facilities for the deaf community. An interim study on LR574 was introduced by Senator Colby Coash during the 103<sup>rd</sup> Legislature, 2<sup>nd</sup> Session. LR574 explores the need for fully integrated residential services for people who are deaf and hard of hearing.

LR574 sought comments from the deaf community and residential providers regarding challenges that the deaf community faces in society, such as access to hearing aids, communication, and isolation. Senator Coash met with members of the deaf community and received emails and letters from several others, including the Lincoln Deaf Club. Members of the deaf community expressed their desires and frustrations with living facilities. Some of their comments are included in this report.

#### **Description of Survey**

The study created a survey and mailed it to 699 institutions throughout Nebraska, seeking responses from group homes for persons with developmental disabilities, people with mental illness, and the aging. Each provider was mailed a copy of the resolution (LR574), a letter explaining the study, and a questionnaire. A copy of the questionnaire, the letter sent to providers, the resolution, and the full results of the study are included with this report.

The study was conducted from June 11 to June 30, 2014. 129 of 699 surveys were fully or partially completed online, or by fax, email, or mail. All survey results not submitted online were entered by staff on the online data tracking website www.SurveyMonkey.com. The website was used to breakdown the statistical analysis of the results and are included with this report.

The facilities chosen to receive the survey are registered as providers and their rosters are listed on the Nebraska Department of Health and Human Services website. Five groups were chosen after consultation with John Wyvill, the Executive Director of Nebraska Deaf and Hard of Hearing. The five groups that received the survey are:

Assisted Living Facilities – 284 registered providers Long Term Care Facilities/Nursing Homes – 227 registered providers Centers for the Developmentally Disabled – 140 registered providers

Group Homes and Child Care Agencies – 31 registered providers

Intermediate Care Facilities for Persons with Developmental Disabilities – 17 registered providers

### **Survey Results**

With the inclusion of facility contact information, nine questions were asked on the survey.

Question 1 Summary: Please circle the best description that most accurately describes your facility: A) Developmentally Disabled Residential Provider B) Assisted Living Facility C)
Nursing Home Facility D) Other (Please Explain): 128 of 129 (99.22%) providers answered question one. Of those respondents, 12 or 9.38% were Developmentally Disabled Residential Provers, 61 or 47.66% were Assisted Living Facilities, 59 or 46.09% were Nursing Home Facilities, and 21 or 16.41% were Other (Other category are listed in the full profile).

Question 2 Summary: How many individuals at your facility are deaf? 128 of 129 (99.22%) providers answered question two. The vast majority of respondents did not have any persons who are deaf at their facility. The most reported were 11 of 622 individuals served by a facility in Omaha.

Question 3 Summary: How many individuals at your facility are hard of hearing? 128 of 129 (99.22%) providers answered question three. Almost every facility reported having an individual that were hard of hearing. The range was 0 to 50.

Question 4 Summary: How many individuals at your facility have an associated hearing loss (onset of hearing loss)? 116 of 129 (89.92%) providers answered question four. The range was 0-78.

Question 5 Summary: How many total individuals are served by your organization? 129 of 129 (100%) providers answered question five. The range was 9-622 with exception of the Nebraska Department of Corrections, which had 5,180 individuals.

Question 6 Summary: What training do you provide to your employees regarding residents that are deaf, hard of hearing, or have an associated hearing loss? 116 of 129 (89.92%) providers answered question six. Overall, most institutions did not provide official training. Most rely on the use of dry erase boards or notepads, employees speaking loudly and clearly while making eye contact with the person with a hearing problem. A few facilities noted that senior staff do take training. Other common answers included taking sign language training, hire outside consultants for training, training for staff on how to approach a deaf person, training for residents on the use of hearing aids, cleaning of hearing aids, change batteries, training for staff on meeting the individual needs of persons that are deaf or hard of hearing, and training on aging for residents, including loss of hearing.

Question 7 Summary: What challenges do you face in serving your residents who are deaf, hard of hearing, or have an associated hearing loss? 113 of 129 (87.6%) providers answered question seven. Several facilities mentioned that they do not encounter any difficulties that they cannot handle. Other common answers included communicating with residents, large group settings, social isolation and planning activities for those with hearing problems, maintenance of hearing aids, cleaning, replacing batteries, misplacement, etc, cost of hearing aids and replacing hearing aids if lost, broken, new batteries, very difficult to get coverage/financing through medicaid, keeping noise levels at a minimum in their rooms, ie: television, radio, and combination of hard of hearing and dementia causes

many problems for staff.

Question 8 Summary: Please read the attached resolution (LR574). As a provider, please comment on the need for fully integrated residential services for people who are deaf and hard of hearing. 62 of 129 (48.06%) providers answered question eight. Over half the respondents chose not to respond to this question or leave feedback. Several facilities felt like the needs of their residents were being fulfilled at this time. Many of the facilities only had a handful of residents that were hearing impaired and felt that they were taking good care of them. It was frequently noted that providers think specialized services are essential for persons who are deaf and hard of hearing, however they feel that facilities that serve only deaf residents would be discriminatory. They also state it would be helpful to have residents screened and tested for hearing loss prior to admittance in a facility.

## **Overall Summary of Survey Results:**

129 surveys were returned out of 694 delivered surveys, resulting in 18.58% return rate.

Many of the respondents noted that Questions 4 & 5 were essentially the same question so they answered that they had the same number of persons that were hard of hearing and had an associated hearing loss.

Several providers stated that they would like to have a training course offered for managers and supervisors so they could then instruct employees how to better communicate with persons who are deaf and hard of hearing. An instructional video or seminar for employees would also be helpful.

There were a couple of responses that expressed concern with the interim resolution. They were worried about the cost associated with building a facility specifically for people who are deaf and hard of hearing. They also mentioned that it could be discriminatory to build a facility specifically for persons who are deaf and hard of hearing. Some were also critical of government oversight and said the costs and paperwork were becoming too burdensome.

Some providers felt that there should be more done to detect the loss of hearing at an earlier age before dementia and other health factors set in so that as people age and lose hearing, they become comfortable and in the habit of using hearing aids.

Many providers did not see the need for a specialized group home for the deaf and hard of hearing. They believe it is better to have these individuals remain in their community where they know their surroundings. Better training, resources, and ways to communicate would be helpful. There seems to be a void in services for those with hearing impairments.

# **Description of Roundtable Discussion**

On September 11, 2014, Senator Coash met with members of the deaf community and the Commission on the Deaf and Hard of Hearing to hear their thoughts and comments regarding the results of the survey. Additionally, members from the deaf community emailed Senator Coash's staff and reaffirmed what the members of the roundtable had expressed. The following five themes are a result of the focus group:

### Considerations/Recommendations

<u>Communication Training:</u> A majority of facility staff have not been trained or receive training for communicating with individuals who are deaf and hard of hearing. This creates a barrier and was the most commented topic in the survey and an issue that kept reoccurring during the discussion. Improving communication training between staff and residents would be extremely beneficial to both parties to remove feelings of isolation among the deaf community. Many providers responded that they would welcome the opportunity for training for staff.

The Nebraska Planning Council on Developmental Disabilities stated in a letter that the additional cost factor would need to be addressed. A provider would need to pay an increased wage to maintain staff who are able to communicate with an individual who is deaf or hard of hearing. Not everyone in DD services utilizes or know American Sign Language. Often individuals, families, and various cultural backgrounds have their own signs and symbols used to communicate. This needs to be taken into consideration when staffing settings in which people who are deaf live.

<u>Isolation:</u> There was great concern among providers and members of the deaf community with the isolation of individuals who are deaf in living facilities. Finding ways for staff to better communicate with individuals who are deaf and hard of hearing would help alleviate isolation. Members of the roundtable discussion stated the last thing they ever want to have happen to them is to end up in a living facility.

<u>Hearing Aids:</u> Providers and members of the deaf community conveyed that there are several issues that arise with the use of hearing aids. Common problems include how to use them, remembering to use them, maintenance, changing batteries, and volume levels. The greatest barrier was the cost for purchase and replacement of hearing aids since they cost roughly \$3000 per aid. Medicare and private insurance do not cover the majority of costs associated with purchasing and fixing hearing aids, while Medicaid¹ can cover a significant portion.

<u>Early Detection</u>: There was disagreement between providers and members of the deaf community regarding early detection for hearing loss prior to entering a living facility. Several providers expressed interest in having all residents tested for hearing loss upon entry into a living facility so that a possible hearing loss detection can be determined and so it can be monitored while in their care. During the roundtable discussion, none of the members of the deaf community thought it was necessary to test for hearing prior to entry of a living facility.

<u>Fully Integrated Living Facility:</u> Providers expressed a great deal of concern regarding fully integrated living facilities for the deaf and hard of hearing. They fear that such facilities or living arrangements would be segregationist and too expensive. In contrast, members of the deaf community would support a fully integrated living facility and would like the option. Members said that it was important to have accessible services in living facilities so they do not find themselves isolated, lonely, and confused. They need living facility staff who can sign, activities with other deaf people, access to video relay services and high speed internet, flashing smoke alarms, and flashing doorbells in their rooms. They were concerned about the feasibility and cost, but did not think it would be a step backwards or

http://www.sos.ne.gov/rules-and-regs/regsearch/Rules/Health\_and\_Human\_Services\_System/Title-471/Chapter-08.pdf

discriminatory. Advocates felt that the lack of trained staff and resulting isolation was more discriminatory because of the lack of interaction in the social setting. Chicago and Arizona have fully integrated facilities for the deaf and hard of hearing, so it could be worth exploring precedents in other geographical locations that could make it feasible in Nebraska.

### **Final Recommendations and Conclusions**

Based on the results of the survey and discussions with members of the deaf community, Senator Coash advises that the Legislature, stakeholders, and community consider the following recommendations.

- 1) Explore additional facilitation of training for free from the Commission on the Deaf and Hard of Hearing. Currently, facility training for staff employees does not fully meet the needs of deaf and hard of hearing residents. The Commission provides training services and the providers should take advantage. The Commission should find ways to provide training videos and printed materials and encourage living facilities to require all staff to have basic training for communicating with residents who are deaf and hard of hearing.
- 2) Several providers stated that they would like to have a training course offered for managers and supervisors so that they could then instruct employees how to better communicate with persons who are deaf and hard of hearing. The Commission should work with providers to produce and offer webbased instructional videos or seminars for staff employees at all levels.
- 3) Explore a systematic screening process to identify scope and need of deaf and hard of hearing residents.
- 4) Similar to Alzheimer's, training for the deaf could be mandated to the license requirement, but at a cost to the state and providers. It is recognized that this would be an unfunded mandate.
- 5) Providers should explore the option for an integrated care facility because a desire exists by the deaf community. Some communities have embraced HUD subsidized independent living communities for the deaf and hard of hearing such as Apache ASL Trails² in Tempe, AZ; New England Homes for the Deaf³ in Danvers, MA; and Emeritus Senior Retirement Community for the Deaf⁴ in Gresham, OR. As the number of individuals who are deaf and hard of hearing increase, other cities and retirement communities are implementing more services for deaf residents in hopes of attracting more deaf and hard of hearing individuals. Members of the deaf community want the choice to be with people who can communicate with them in their preferred language or form of communication. Facilities that promote independence and accessibility for the deaf and hard of hearing should be be considered.

Sincerely,

Senator Colby Coash Legislative District 27

<sup>2</sup> http://www.apacheasltrails.com/main.html

<sup>3</sup> http://www.nehd.org/

<sup>4</sup> https://www.emeritus.com/oregon/gresham-retirement-community-for-the-deaf/chestnut-lane

From: Lincoln Deaf Club

To: David Slattery Legislative Aide; Senator Colby Coash State Capitol – Room 2028 P.O. Box 94604 Lincoln, NE 68509

September 20, 2014

Dear Mr. Slattery,

The Lincoln Deaf Club (LDC) members want to thank you for your work with LR 574. Because English is not our first language, we decided to all sign this letter to show our support. We asked Nancy Brt to translate our signed message to written English. We would love to have you come to one of our clubs where we could tell you face to face how we feel using our own language with a sign language interpreter. But for now, below is our collective feelings and experiences.

We want you to know that it is very important to us to have accessible services in nursing homes, assisted living centers and group homes. Some of us live in nursing homes now, some of us live in group homes now. Most of us will need these services someday. For those of us already living in these facilities, we find ourselves very isolated, lonely and confused. There are no staff who can sign to us. And we are often the only deaf person in the whole facility. Often hearing people believe all deaf people can read lips. So most of the time they just talk to us as if we can hear or read lips. Most of us can not read lips and our understanding of written English is limited. So our interactions are mostly based on facial expressions.

If we had a facility of our own, or a place that already serves older people or people with developmental disabilities or people who have mental illness what kind of things would we need? We need staff who work with us to be able to sign to us. And then in return be able to understand us when we respond to them in sign language. We want activities geared toward deaf people with staff who can sign. We need access to video relay services. To have video relay you need to have high speed internet. That costs about \$50 a month. When you live in these places often \$50 is all the money you have to spend in a month. Flashing smoke alarms, and flashing door bells to our rooms so we know someone wants to come in.

We want other deaf people to live with so we have someone to talk to at meals and during activities. We want young deaf people to work with us too. Deaf people need good jobs too. How wonderful for both of us to be able to communicate with each other. Janitors, cooks, nursing staff, therapists, activities staff, etc. are all positions deaf people are capable of doing. But in a hearing world they don't have opportunities for these meaningful jobs where they don't have to worry about being understood. There are also hearing people who know sign language and want opportunities to use it.

Thank you for your work on LR 574. If you would like to meet us in person, please contact Nancy Brt. Our meetings are once a month in the church basement of Heritage Presbyterian Church in Lincoln, NE. Nancy can help you contact any of us who signed this letter.

Lincoln Deaf Club Members